National Center on Birth Defects and Developmental Disabilities

Annual Report Fiscal Year 2014

Protecting People and Preventing Complications of Blood Disorders

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) made significant progress in its efforts to improve the lives of people with blood disorders in 2014.

Blood disorders - such as deep vein thrombosis, hemophilia, and thalassemia - affect millions of people each year. Men, women, and children of all backgrounds live with the complications of these conditions, many of which are painful and potentially life-threatening. NCBDDD works to reduce the public health burden of blood disorders by contributing to a better understanding of blood disorders and their complications; developing, implementing and evaluating prevention programs; providing information to consumers and health professionals; and encouraging action to improve the quality of life for people living with these conditions.

Accomplishments

- Highlighted NCBDDD's role in meeting the emerging public health needs of people with blood disorders in the September 20, 2014 issue of the American Journal of Preventive Medicine. Five papers addressed CDC's efforts to strengthen surveillance activities for blood disorders and expand partnerships to provide a better understanding of the health status, needs, economic burden and health-related quality of life of people with nonmalignant blood disorders.
- Launched a "Webinar Series on Bleeding and Clotting Disorders" to provide evidence-based information on new research, interventions, emerging issues of interest in blood disorders, as well as innovative approaches in collaborations and partnerships.
- Launched a website on Vitamin K Deficiency Bleeding that includes fact sheets, frequently asked questions, articles, videos, podcasts, and personal stories to increase parent and provider understanding of the importance of vitamin K shots for newborns.
- Published a new surveillance report to disseminate the information collected by the Universal Data Collection system during the years 2005 through 2009. The report contains information about the demographic characteristics of the participants, their blood and factor product use, and the occurrence and treatment of joint and infectious diseases.
- Published the results of a six-year study, called the Hemophilia Inhibitor Research Study (HIRS), which was designed to test the feasibility of conducting national monitoring for inhibitors among people with hemophilia in the United States. Key findings were summarized and posted to the web.
- Published an article that describes the efforts of the states participating in the Registry and Surveillance System for Hemoglobinopathies (RuSH) and federal agencies to design the project and the methods used to collect data for the system. The key findings were summarized on the web.


Strengthening surveillance activities and expanding partnerships
Conducting a webinar series on bleeding and clotting disorders
Disseminating health information about people with bleeding disorders
Educating the public about vitamin k deficiency bleeding
Testing the feasibility of national monitoring for inhibitors
How is NCBDDD Protecting People from Blood Disorders?

Looking to the Future

CDC will improve the understanding of complications of blood transfusions used to treat people with thalassemia and sickle cell disease, as well as the causes and risk factors for developing inhibitors in people with hemophilia. We will evaluate and promote the use of periodic inhibitor screening, monitor complications from blood and treatment products, and assess the effectiveness of prevention strategies. We remain focused on healthcare-associated VTE prevention; improving laboratory techniques; and increasing provider and public knowledge and awareness of the signs and symptoms of blood disorders, the importance of early recognition and diagnosis, and referrals to specialists and comprehensive care.

Notable 2014 Scientific Publications

Soucie JM, et al. A study of prospective surveillance for inhibitors among persons with haemophilia in the United States. Haemophilia. 2014;20:230-7.

Skinner MW, et al. The national haemophilia program standards, evaluation and oversight systems in the United States of America. Blood Transfus. 2014;12 Suppl 3:s542-8.

Sidonio RF, et al. and the HTCN. Females with FVIII and FIX deficiency have reduced joint range of motion. Am J Hematol. 2014;89:831–836.

Payne AB, et al. High factor VIII, von Willebrand factor, and fibrinogen levels and risk of venous thromboembolism in blacks and whites. Ethn Dis. 2014 Spring;24(2):169-74.

Miller CH, et al. Gender, race and diet affect platelet function tests in normal subjects, contributing to a high rate of abnormal results. Br J Haematol. 2014 Jun;165(6):842-53.

Streiff MB, et al. CDC Grand Rounds: preventing hospital-associated venous thromboembolism. MMWR Morb Mortal Wkly Rep. 2014 Mar 7;63(9):190-3.

Yusuf HR, et al. Risk of venous thromboembolism among hospitalizations of adults with selected autoimmune diseases. J Thromb Thrombolysis. 2014 Oct;38(3):306-13.

Rhynders PA, et al. Providing Young Women with Credible Health Information about Bleeding Disorders. Am J Prev Med. 2014 Sep 9. pii: S0749-3797(14)00407-3.

Hulihan MM, et al. State-based surveillance for selected hemoglobinopathies. Genet Med. 2014 Jul 3. doi:10.1038/gim.2014.81.

Mainous AG 3rd, et al. Elevated transferrin saturation, health-related quality of life and telomere length. Biometals. 2014 Feb;27(1):135-41.

Spotlight On:
Hemophilia Federation of America

Hemophilia Federation of America (HFA) is a national grassroots community organization that was formed in 1994 to assist all people living with a bleeding disorder. HFA provides programing and advocacy support for those with bleeding disorders to encourage community members to lead healthy and active lifestyles and have access to the care they need to manage their condition. The needs of the community are incredibly unique which is why having strong advocates, to ensure access to life-saving medication and healthcare providers, is crucial.

Growing up, my brother had hemophilia and I have two cousins that are also affected by the condition. While very familiar with the particular needs of the community, I had been away from it for some time. Since starting at HFA over a year ago, I have found an area where I can use my government relations and advocacy experience for something I am passionate about. HFA delivers programs that help adult men cope with their bleeding disorders, moms and dads become more involved in their child's healthcare, and give women a much needed voice. I have helped to develop an app that speaks specifically to the needs of women with bleeding disorders, allowing them to track their menstrual cycles and bleeds. From an advocacy perspective, my work here has allowed me to fight for legislation to keep medication affordable both federally and in the states; to help educate payers on the specific needs of the community; and overall ensure that the community has the care they need. I've been able to help individuals solve specific problems with discrimination and denial of care. I feel fortunate to be a part of such a successful group of advocates and look forward to continuing HFA's mission of supporting the community.

- Katie Verb

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